

**Comment of the National Citizens Coalition for Nursing Home Reform
For the “Listening Session”
Of the 2005 White House Conference on Aging
By
William F. Benson, President

September 9, 2004**

My name is Bill Benson and I am the President of the Board of Directors of the National Citizens’ Coalition for Nursing Home Reform (NCCNHR). On behalf of NCCNHR’s board and staff, led by Ms. Alice Hedt, I am before you to request that the issues facing the nation’s 17 million residents in nursing homes and board and care facilities, including assisted living, be addressed at the upcoming White House Conference on Aging in 2005. It is often said that a society can be judged by how its most vulnerable members are treated, and residents are truly vulnerable due to a variety of factors: isolation (over 40% have no immediate families or friends who visit regularly); mental status (it is estimated that from 40 – 60% have some type of dementia); and medical conditions that necessitate that they receive long-term care services (54% are bedfast or chair bound, 29% have contractures, 7% with pressure sores).

While there is much discussion about home and community-based care, NCCNHR maintains that the demographics of the Baby Boomers and many elders’ lack of caregivers will necessitate nursing homes in the foreseeable future. In addition, NCCNHR is concerned that all elders who reside in licensed facilities in the community receive adequate and appropriate care, including those who receive services through Medicaid waiver programs. Because of the utilization of nursing homes for rehabilitation and post-acute care, it is estimated that one-half of all women and one-third of all men will spend some time in a nursing home during their life.

For almost 30 years, NCCNHR has been a national voice for persons who live in long-term care facilities. As a membership organization of residents, family members, citizen advocates, long-term care ombudsmen, researchers, and others concerned about quality of life and care in long-term care, we welcome the opportunity to help shape the discussions related to facility-based services, including the following issues:

- Staffing is the primary issue that determines the quality of all of long-term care. The workforce has to be adequate in terms of numbers of staff, training, supervision, benefits and compensation. The 2002 CMS study of the appropriateness of nurse staffing ratios, as well as other studies, clearly show that there is a minimum staffing level that is absolutely essential to ensuring that basic care is provided to residents. Yet, a majority of facilities do not staff at that level and 92% of nursing homes do not have enough nursing assistants to provide adequate care. In addition, Long-term Care Ombudsman data over the last five years indicate that the most frequent complaints from nursing home residents are directly related to staffing issues – responses to call bells, residents not being treated with dignity or respect, accidents and improper handling, personal hygiene, and staff being unresponsive or unavailable.
- Quality of life is an essential topic to examine because residents have the right under the Nursing Home Reform Act to an environment that humanizes and individualizes each resident and ensures that each resident is treated with dignity and respect. Individualized care planning is central to quality of care. Culture change activities such as person-centered care practiced by the Pioneer Network should become the standard of all care and not just the practices of a few facilities determined to improve conditions for their own residents.
- Systems established by government to ensure that residents are not neglected or abused must be enforced in all long-term care facilities, including those that receive funding through Medicaid waiver programs. Enforcement must be timely, fair and consistently applied. Complaints should be responded to quickly and there must be coordination between states' Adult Protective Services and Licensure and Certification agencies.
- The Long-Term Care Ombudsman Program is essential to the long-term care system because residents need a voice to handle individual grievances as well as systemic issues. However, several OIG reports as well as the 1985 Institute of Medicine study of the ombudsman program – *Real People: Real Problems* – highlight that this important program is underfunded and under-resourced. (Note: the program serves all licensed facilities and currently handles over 260,000

complaints, 296,000 one-on-one consultations, and 10,000+ community education programs.)

- The needs of specific groups within the long-term care population need to be examined and addressed. There are several contemporary issues of great concern to NCCNHR and that believe deserve national examination. These include the care of aging prisoners (i.e., within or outside of the current nursing home system); the co-location of elders needing nursing home care and younger populations; the myriad of multicultural issues in facility-based long-term care (i.e., between residents themselves, residents and staff, and staff and management); and, end-of-life care that is humane and individualized.

The National Citizens' Coalition for Nursing Home Reform looks forward to the 2005 White House Conference as an opportunity for a thorough examination of the long-term care system and the development of strategies that will result in improved quality of care and quality of life for all elders, including those who will need to live in long-term care facilities. Our staff and board appreciate the opportunity to share ideas in this planning process and look forward to participation in the conference itself.

For additional information please contact:

William Benson, NCCNHR President
Alice H. Hedt, NCCNHR Executive Director

National Citizens' Coalition for Nursing Home Reform
202-332-2275
www.nursinghomeaction.org